

## Factors affecting fear of breast cancer recurrence in a developing country

Fear of breast cancer

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### Abstract

**Aim:** The survival and treatment outcomes of breast cancer patients have improved dramatically in the last decades. In this study, we aimed to study Fear of cancer recurrence (FOCR) in breast cancer.

**Material and Method:** This is a descriptive correlational study on 313 non-metastatic breast cancer patients. The questionnaire consisted of a demographic checklist and a short form of fear of progression questionnaire. The five-point Likert scale was used to score responses to 12 items. A score of 34 or above indicates a dysfunctional level of FoP-Q-12.

**Results:** The mean age of the patients was 52.63 years  $\pm$ 10.65 with a mean time of follow-up of 50.7  $\pm$ 35.19 months. The mean total score was low 30.78  $\pm$  30.78; 95%CI: 29.64-31.91. The highest score was for "Being afraid of the possibility that children could contract cancer" (3.24  $\pm$  1.706; 95% CI: 3.24-3.05), and the lowest score was for "Fear of becoming less productive at work" (1.75  $\pm$  1.285; 95% CI: 1.6-1.89). FOCR was affected by the mean age of both the patient and the children (p-value = < 0.001), reaching a high statistical significance; whereas FOCR was higher in patients without a university degree and not living with spouse and children (p-value: 0.005 and 0.063). On multivariate analysis, FOCR was only associated with a higher university degree (OR 0.301, 95% CI: 0.115-785, P value: 0.014).

**Discussion:** Studying FOCR is important to improve the quality of life of cancer survivors. Egyptian breast cancer patients experienced a low level of fear of cancer recurrence. This may be related to strong religious beliefs among this population. FOCR was only associated with not having a high University degree.

### Keywords

Breast cancer; Fear of recurrence; Fear of progression; Egypt

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## Introduction

The survival and treatment outcomes of breast cancer patients have improved dramatically in the last decades [1]. This may be due to better risk stratification according to biomarkers, tailoring hormonal therapy along with combination chemotherapy, targeted therapy and immunotherapy [2].

There is a growing interest in the quality of life of surviving patients, as they may experience symptoms related to side effects of treatment. They may also suffer from emotional distress as well as impairment of physical and psychological wellbeing [3]; these factors may lead the patient to worry about cancer recurrence [4].

Fear of cancer recurrence (FOCR) was defined as “the worry or anxiety of the patient about the recurrence of the tumor in the same part of the body or spread to other organs” [5]. Factors affecting FOCR included age, sex, time since diagnosis, quality of life, anxiety, and depression [6, 7]. This fear is one of the major concerns and unmet needs of breast cancer patients [8]. The 12-item questionnaire FoP-Q-12 is one of the instruments for measuring FoP. It has been successfully applied to samples of breast cancer patients or samples dominated by breast cancer patients [9]. Personalized Medicine, maintenance therapy and screening of cancer recurrence are very important as they are accompanied by relevant psychological disturbance [10, 11].

FOCR has not been well studied in the Middle East and only a few studies have been conducted [12]. In Egypt, depression and anxiety were higher in cancer patients when compared to control on the Psychological Distress using the Hospital Anxiety and Depression Scale [13]. To our knowledge, FOCR has not been previously studied in either Egypt or other Arab countries. The aim of this work is to investigate FOCR and its predictive factors among Egyptian cancer patients.

## Material and Methods

This is a descriptive correlational cross-sectional study on 313 non-metastatic breast cancer patients. Patients were recruited from March to June 2017. The study was approved by the clinical oncology department ethical committee as well as the Faculty of Medicine Cairo University ethical committee (03-05-17). Informed consent was obtained from all participants prior to participation in the study.

The study included all non-metastatic breast cancer patients aged  $\geq 18$  years attending the follow up out-patient clinic. Patients should have completed active treatment including chemotherapy and radiotherapy; however, they may be still on hormonal treatment. The time interval from diagnosis was at least 6 months. The participants must have been aware of their diagnosis and should have been under the normal physical and psychological conditions to participate in the survey.

The questionnaire consisted of a demographic checklist and a short form of fear of progression questionnaire [9], which was translated into Arabic and back-translated by two independent English translators. This was then revised by 18 academic members affiliated to Cairo University. The internal consistency was calculated on a sample of 20 pilot patients. The  $\alpha$  Cronbach coefficient was 0.83. The five-point Likert scale was used to score the response of the 12 items of the questionnaire. It ranged from one (never) to 5 (very often).

The final score was a sum of all items. A score of 34 or above indicates a dysfunctional level of FoP-Q-12 (Herschbach et al., 2010; Hinz et al., 2015) [14,15].

## Procedure

The data collection was done by two oncologists inviting 320 out-patients using a private face to face interview. Most of the patients, (97.8 %, 313 patients) accepted to participate and only 7 patients refused. The aim of the study was explained to all patients, and only those accepting to give informed consent were included in the study. The extraction of medical data was done by the researchers from the medical records. This included staging, time from diagnosis and treatment received.

## Statistical analysis

All data were statistically studied using descriptive analysis as well as FOCR in relation to different clinico-epidemiological factors. Univariate and multivariate analyzes using the COX regression module were performed to test the power of the relationship between the independent variables and FOCR. A probability value (p value) less than 0.05 was considered significant. The statistical calculations were done using Microsoft Excel version 7 and SPSS statistical software (Statistical Package for Social Sciences).

## Results

The study included 313 breast cancer patients. The mean age was  $52.63 \pm 10.65$  years, and the mean follow-up time was  $50.7 \pm 35.19$  months. Most of the cases were married (73%, 229), housewife (80.8%, 253), and living with spouse and children (57.8%, 181). The majority of participants (63.9%) had some kind of education either a diploma degree (28.8%), primary education (23%), or university degree (12.1%). The rest of them were illiterate (36.1%, 113). Patients presented as staged I, II, III (9.9%, 50.5%, and 39.6% respectively). The Socio-demographic and medical characteristics of the participants are shown in Table 1.

All patients accepting to take the questionnaire gave informed consent. The responses of the participants to all items of the fear of progression questionnaire had a mean total score of  $30.78 \pm 30.78$ ; 95%CI: 29.64-31.91. The highest score was for “Being afraid of the possibility that the children could contract cancer” ( $3.24 \pm 1.706$ ; 95% CI: 3.24-3.05), followed by Anxiety about what will happen to the family if something happens to the patient ( $3.22 \pm 1.667$ , CI 3.03-3.4) and “Being afraid of pain” ( $3.15 \pm 1.539$ , 95% CI: 2.98-3.32). The lowest score was for “Fear of becoming less productive at work” ( $1.75 \pm 1.285$ ; 95% CI: 1.6-1.89) and “Fear of no longer being able to pursue hobbies” ( $1.8 \pm 1.26$ ; 95%CI: 1.66-1.94). Responses of the participants to all items of fear of progression questionnaire are shown in Table 2.

According to demographic and disease characteristics of the patients by fear score, the patients were divided according to whether they have a high or low score for FOCR with a cut off value of 34. The majority of these patients had a low score (59.1% vs 40.9%, p-value: < 0.001). FOCR was affected by the mean age of the patient and the mean age of children (p-value= < 0.001), reaching a high statistical significance. Whereas FOCR was higher in patients without a university degree and not living with a spouse and children (p-value: 0.005 and 0.063).

**Table 1.** Socio-demographic and medical characteristics of the participants

Variable	N (%)
<b>Marital status</b>	
Single	11 (3.5)
Married	229 (73.2)
Divorced/widow	73 (23.3)
<b>Educational level</b>	
Illiterate	113 (36.1)
Primary	72 (23)
Diploma degree	90 (28.8)
University degree	38 (12.1)
<b>Employment status</b>	
Employed	25 (8)
Housewife	253 (80.8)
Worker	31 (9.9)
Retired	4 (1.3)
<b>Living situation</b>	
Single (alone)	28 (8.9)
With spouse	41 (13.1)
With children	53 (16.9)
With spouse and children	181 (57.8)
With parent	10 (3.2)
<b>Time since surgery</b>	
Mean (±SD)	50.7 (±35.19)
<b>Stage</b>	
I	31 (9.9)
II	158 (50.5)
III	124 (39.6)
<b>Type of primary treatment</b>	
Chemotherapy	213 (68.1)
Radiotherapy	214 (68.4)
Surgery	313 (100)
<b>Mean age in years</b>	
Mean (±SD)	52.63 (±10.65)

**Table 2.** Responses of participants to all items of fear of progression questionnaire

Question	Mean	SD	CI 95%
Q1 Being afraid of disease progression	2.92	1.527	2.75-3.09
Q2 Being nervous prior to doctors' appointments or periodic examinations	2.63	1.584	2.45-2.81
Q3 Being afraid of pain	3.15	1.539	2.98-3.32
Q4 Being afraid of becoming less productive at work	1.75	1.285	1.6-1.89
Q5 Having physical symptoms, e.g., rapid heart-beat, stomach ache, nervousness	2.89	1.644	2.71-3.08
Q6 Being afraid of the possibility that the children could contract cancer	3.24	1.706	3.24-3.05
Q7 Being afraid of relying on strangers for activities of daily living	2.46	1.617	2.28-2.64
Q8 Being afraid of no longer be able to pursue hobbies	1.8	1.26	1.66-1.94
Q9 Being afraid of severe medical treatments in course of the illness	2.33	1.555	2.15-2.5
Q10 Worrying that medications could damage the body	2.29	1.518	2.13-2.46
Q11 Worrying about what will happen to the family if something happens to the patient	3.22	1.667	3.03-3.4
Q12 Being afraid of not being able to work anymore	2.1	1.475	1.94-2.27
Total score	30.78	10.203	29.64-31.91

**Table 3.** Demographic and disease characteristics of the patients by fear score

Variable	FoP-Q-12 score		p value
	<34	≥34 (dysfunctional)	
<b>Marital status</b>			
Single, divorced, widow	53 (63.1%)	31 (36.9%)	0.385
Married	132 (57.6%)	97 (42.4%)	
<b>Educational level</b>			
Illiterate	72 (63.7%)	41 (36.3%)	0.005
Primary	45 (62.5%)	27 (37.5%)	
Diploma degree	40 (44.4%)	50 (55.6%)	
University degree	28 (73.7%)	10 (26.3%)	
<b>Living situation</b>			
With spouse and children	86 (65.2%)	46 (34.8%)	0.063
Others	99 (54.7%)	82 (45.3%)	
<b>Children</b>			
No	12 (57.1%)	9 (42.9%)	0.85
Yes	173 (59.2%)	119 (40.8%)	
<b>Age of children</b>			
Mean ± SD	26.49 (±10.97)	21.9 (±9.03)	< 0.001
<b>Number of children</b>			
Mean ± SD	3.39 (±1.862)	3.18 (±1.599)	0.289
<b>Having daughters</b>			
No	42 (58.3%)	30 (41.7%)	0.879
Yes	143 (59.3%)	98 (40.7%)	
<b>Chemotherapy</b>			
No	65 (65%)	35 (35%)	0.146
Yes	120 (56.3%)	93 (43.7%)	
<b>Radiotherapy</b>			
No	66 (66.7%)	33 (33.3%)	0.064
Yes	119 (55.6%)	95 (44.4%)	
<b>Age of patient (years)</b>			
Mean ± SD	54.7 (±10.96)	49.64 (±9.45)	< 0.001
<b>Time since initial diagnosis (months)</b>			
Mean ± SD	51.11 (±35.92)	50 (±34.23)	0.784
Total	185 (59.1%)	128 (40.9%)	< 0.001

Factors affecting FOCR are shown in Table 3.

In multivariate logistic regression analysis, FOCR was not associated with patient age, living condition, age of children, or treatment received. It was only associated with a higher university degree (OR 0.301, 95% CI: 0.115-785, p-value: 0.014).

**Discussion**

After an extensive review of the literature, this is the first study to investigate FOCR and the factors affecting it among cancer patients in Egypt and Arab countries. Also, it included the largest number of breast cancer patients among the few studies in the Middle East.

The study showed that most of the participants had a low score <34 (59.1% vs. 40.9%, p value = < 0.001), with a mean total score of 30.78. The highest score was for “Being afraid of the possibility that the children could contract cancer” followed by “Worrying about what will happen to the family if something happens to the patient”, and “Being afraid of pain”. The lowest score was for “Fear of becoming less productive at work” and

“Fear of no longer being able to pursue hobbies”. FOQR was only associated with a lack of a high University degree.

The incidence of moderate to high fear was 40.9%. This was in accordance with the results (49%) found in Simard, 2013, a systematic review to identify quantitative studies associated with FOC and different types of cancer [6]. The mean score was 30.78. This was close to the mean (24.9) recorded by Hinz et al. in 2014. In their study, they found only 16.7 % of the participant scoring above the cut-off score. It showed the reliability of the short form of the fear of progression questionnaire with a Cronbach’s alpha of 0.9. The study included 2059 cancer patients six months after completion of their rehabilitation program. Females and younger patients showed higher scores [15].

This low score was in accordance with a meta-analysis done by six German registries including 2671 breast cancer patients. They used the short form of fear of the progression questionnaire. The majority (82%) had a low level of fear. Patients with moderate and high levels of fear accounted for 11% and 6%, respectively. However, the number of these patients was lower than in the present study (17% vs. 40.9%) [16]. Another study showed low to moderate levels of fear in African Americans with breast cancer [17]. Moreover, a study conducted on patients with colon cancer found that only 38% of them suffer from high fear [18].

Time since the initial diagnosis did not show statistical significance in our study. This was contradictory to many other studies showing that FOQR decreases with time elapsed since the diagnosis [17, 19, 20]. A Belgium study showed a significant interaction effect between age and 18 month follow-up ( $P < .02$ ). This interaction suggests that the course of FCR over time depends on the age of the participants with older breast cancer survivors reported decreasing levels of FCR [21].

FOCR was affected by the mean age of the patients with high statistical significance ( $p$ -value:  $< 0.001$ ). This is in accordance with a big study from the USA including a 2010 survey among breast cancer patients. The study included 2,668,697 survivors. In univariate analysis, worry about recurrence was positively correlated with the present age and radiotherapy ( $p$ -value 0.03 and 0.04, respectively) [22].

Younger Age significantly affected FOQR  $< 0.001$  in the present study, and this was similar to other studies [15, 17]. There was a great association with young age and considering oneself as a cancer patient with moderate and high FOQR in a German meta-analysis. (Odds ratio=3.00, confidence intervals=1.91-4.73 and odds ratio=3.36, confidence intervals=2.66-4.25 respectively) [16].

The age of children affected the FOQR in many studies. Having younger children raises the burden on the mother as a primary caregiver. This increases her worry about what will happen to her children if she gets recurrence, and increases the sense of fear [16]. Other studies showed that motherhood increases the fear of leaving children, regardless of their age [23]. In the present study, the mean age of children affected the score of FOQR, reaching high statistical significance ( $p$ -value:  $< 0.001$ ). Our study showed that FOQR was lower among patients with a university degree and living with spouse and children ( $p$ -value: 0.005 and 0.063), and in multivariate analysis, a higher score

of FOQR was only correlated with patients without university degree. This was comparable to a descriptive and correlational study done in the Middle East by Aghdam et al. in 2014 on 129 cancer patients of both sexes and different diagnoses, showing that FOQR was associated with a lower level of education and not living with spouse and children. Multivariate analysis in this Iranian study showed the highest association with female sex, being breast cancer, not having a university degree, and receiving radiotherapy ( $p$ -value= 0.021, 0.044, 0.008 and 0.094, respectively) [12].

In the present study, the Egyptian patients experienced a low level of fear of cancer recurrence. This may be related to strong religious beliefs among such patient populations.

#### **Study limitation**

The limitation of the study is that only breast cancer patients were included. These were only female, out-patients with no consideration for hospitalization. Also, the study was cross-sectional, including every patient only once in the questionnaire. The study design did not include quality of life or any psychological assessment. This was considered as a screening study as it was the first to address this issue in the region.

#### **Future perspectives**

Further studies should include patients with different types of cancer in the Middle East. Male sex should be included. Also, the future studies should include patients from different cultures and regions. Studies should be longitudinal evaluating the fear of the same patient several times since the diagnosis to determine whether it affected the extent of fear. This should include early and late assessment. Also, there should be a correlation between the quality of life and any associated psychological disturbance, especially anxiety and depression.

#### **Conclusion**

This study conducted in Egypt showed a low score of FOQR. Higher level was associated with patients without university education. The short form of FOCQ proved to be a rapid and reliable method to screen breast cancer patients under follow-up. This can provide high risk survivors with psychological support and assistant programs.

#### **Scientific Responsibility Statement**

*The authors declare that they are responsible for the article’s scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.*

#### **Animal and human rights statement**

*All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. No animal or human studies were carried out by the authors for this article.*

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#### **Conflict of interest**

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